Fetal Alcohol Syndrome in Alaska, 1977 through 1992: An Administrative Prevalence Derived from Multiple **Data Sources**

ABSTRACT

Objectives. The prevalence and characteristics of fetal alcohol syndrome cases and the usefulness of various data sources in surveillance were examined in Alaska to guide prevention and future surveillance

Methods. Sixteen data sources in Alaska were used to identify children with fetal alcohol syndrome. Medical charts were reviewed to verify cases, and records were reviewed to provide descriptive data.

Results. Fetal alcohol syndrome rates varied markedly by birth year and race, with the highest prevalence (4.1 per 1000 live births) found among Alaska Natives born between 1985 and 1988. Screening and referral programs to diagnostic clinics identified 70% of all recorded cases. The intervention program for children 0 to 3 years of age detected 29% of age-appropriate cases, and Medicaid data identified 11% of all cases; birth certificates detected only 9% of the age-appropriate cases.

Conclusions. Our findings indicate a high prevalence of fetal alcohol syndrome in Alaska and illustrate that reliance on any one data source would lead to underestimates of the extent of fetal alcohol syndrome in a population. (Am J Public Health. 1998;88:781-786)

Grace M. Egeland, PhD, Katherine A. Perham-Hester, MS, Bradford D. Gessner, MD, Diane Ingle, BA, James E. Berner, MD, and John P. Middaugh, MD

Introduction

Fetal alcohol syndrome, characterized by central nervous system impairment, growth deficiency, and dysmorphic facial features, could be among the most common preventable causes of mental retardation in the United States.² Fetal alcohol syndrome is a lifelong disability involving considerable personal³ and societal^{2,4} costs. The annual costs associated with this condition in the United States have been estimated to range from \$74.6 million⁴ to \$321 million,² depending on population incidence estimates. As a result of the high costs associated with fetal alcohol syndrome and the presence of a known teratogen, 5-8 the prevention of fetal alcohol syndrome has become a national health priority.9

Alaska has the highest rate of alcoholrelated hospitalizations in the nation, 1 along with one of the highest per capita alcohol consumption levels, 11 and it is among the top 5 states in the country in terms of prevalence of binge drinking (consumption of more than 5 drinks at any 1 time per month) or drinking 30 or more drinks per month among women of reproductive age. 12.13 Therefore, there has been a long-standing assumption that Alaska has one of the highest fetal alcohol syndrome rates in the nation.¹⁴ In this report, we examine the usefulness of a variety of data sources in fetal alcohol syndrome surveillance and attempt to determine the administrative prevalence and characteristics of fetal alcohol syndrome in Alaska. These data will be used to guide and evaluate prevention efforts in the state. Also, they may assist in appropriate development of surveillance protocols for the nation.

Methods

We identified potential fetal alcohol syndrome cases through the private medical sector, the state of Alaska, the Indian Health Service, and regional native health corporations. The pediatric practices selected were referral centers for fetal alcohol syndrome. and the hospitals selected serve a sizable portion of the state's population. In 5 sources that had computerized International Classification of Diseases (9th Revision; ICD-9) data, we searched for ICD-9 code 760.71 (noxious influence of alcohol on fetus or newborn via placenta or breast milk). 15 For 2 sources, only ICD-9 code 760.7 (any noxious influence affecting the fetus or newborn) was available. The range of years searched by source varied as a result of different program initiation dates or variable availability of data. Details regarding the method of identifying potential fetal alcohol syndrome cases are presented in Table 1. Medical charts available were obtained and reviewed. We accepted a case of fetal alcohol syndrome when medical charts included notations of all of the following: (1) fetal alcohol syndrome suspected or diagnosed by

Grace M. Egeland is with the National Center for Environmental Health, Centers for Disease Control and Prevention, and the Division of Public Health. Alaska Department of Health and Social Services, Anchorage. Katherine A. Perham-Hester, Bradford D. Gessner, Diane Ingle, and John P. Middaugh are with the Division of Public Health, Alaska Department of Health and Social Services. James E. Berner is with the Indian Health Service, Alaska Area Native Health Service, Anchorage.

Requests for reprints should be sent to Grace M. Egeland, PhD, State of Alaska, Department of Health and Social Services, Division of Public Health, Section of Epidemiology, PO Box 240249, Anchorage, AK 99524-0249.

This paper was accepted April 16, 1997.

TABLE 1—Sources of Data and Method of Identifying Potential Fetal Alcohol Syndrome (FAS) Cases in Alaska

Source of Data Identification Method

Private sector

Hospitals

Anchorage and Fairbanks

Pediatricians Anchorage Fairbanks

State of Alaska^a

Infant Learning Program

Health Care Program for Children with Special Needs

Clinic: cleft lip and palate

Clinic: genetics

Clinic: alcohol-exposed children

Rural nursing station

Medicaid claims Birth certificates Death certificates

Alaska Native Indian Health Service case file

Regional native health corporations (serving the interior and southeast regions of Alaska)

Native Medical Center, Anchorage

ICD-9 code 760.71 on discharge data tapes from 1988-1992 (largest and fourth largest hospitals in the state)

List of potential FAS patients served in 1993

List of FAS/alcohol-exposed patients served from 1990-1992

Potential FAS children 0-3 years of age seen in 1991/92 ICD-9 code of 760.71 on data tape of program recipients 0-21 years of age served in 1992

Potential FAS children evaluated from 1983-1993 Potential FAS children evaluated from 1977-1992

Children evaluated in 1992/93

Potential FAS children identified in a public health nursing caseload

in 1993

ICD-9 code of 760.71 on tapes in 1989/90 FAS check box on certificates filed in 1989/90

ICD-9 code 760.7 as contributing/underlying cause of death from 1977-1990

Patients seen for an alcohol-related diagnosis during 1985-1993; statewide active screening in 1986 followed by ongoing active screening in Anchorage area and passive reporting from 12 autonomous regional native health corporations

ICD-9 code 760.71 on discharge data tapes in 1989/90 for interior Alaska and 1986-1992 for southeast Alaska

ICD-9 code of 760.71 on discharge data tapes from 1985-1992 (third largest hospital in the state)

a physician, (2) prenatal alcohol exposure or a maternal history of alcohol abuse, (3) characteristic fetal alcohol syndrome facial features, (4) growth deficiency, and (5) central nervous system impairment.

Evidence of facial features characteristic of fetal alchohol syndrome included a physician notation of fetal alcohol syndrome stigmata or any of the following: short palpebral fissures, long or flat philtrum, thin upper lip, hypoplastic maxilla, short nose relative to normal length midface, or flat nasal bridge. Growth deficiency was defined as height or weight less than or equal to the 10th percentile for given age^{16,17} or a chart notation of failure to thrive. Evidence of central nervous system impairment included any of the following: structural anomalies (microcephaly or hydrocephaly), other neurologic anomalies (seizures, abnormal electroencephalogram, hypertonia, hypotonia, cerebral palsy, tremors, hearing deficits of neurosensory origin, or microphthalmia), or behavioral or cognitive anomalies (mental retardation, hyperactivity, short attention span or attention deficit disorder, learning disability, developmental delay [including fine or gross motor delay or speech or language delay], behavior or conduct problems, or school failures). 18

In addition to data regarding individuals who met the case definition, we also present results for individuals who had a physician chart mention of suspected or diagnosed fetal alcohol syndrome but who may or may not have met the definition.

Number of live births in Alaska from 1977 to 1982, the period in which the majority of identified fetal alcohol syndrome patients were born, provided the denominator. We determined child's race by race of mother noted on the birth certificate; child's race as noted in the medical chart supplemented missing data. We obtained demographic information on biological mothers through chart abstraction or birth certificates. Information for the great majority of biological fathers was unavailable. We sought to determine which data source(s) would be most useful for statewide surveillance by determining which sources identified the greatest percentage of fetal alcohol syndrome cases.

Results

We identified a total of 630 potential fetal alcohol syndrome cases from all of the available data sources. Five hundred sixty-

eight patients (90%) had medical charts available (Table 2). Prenatal alcohol exposure or a maternal history of alcohol abuse was noted for 462 of these 568 individuals (81%). A physician notation of diagnosed or suspected fetal alcohol syndrome was noted for 248 (44%) individuals, and 145 (26%) met all 5 criteria of the case definition. A total of 71 different physicians made a chart notation of the syndrome.

Characteristics and Administrative Prevalence of Fetal Alcohol Syndrome

Among the 145 case patients, 53% were male. Eighty-three percent were Alaska Native, 12% were White, and 4% were Black. Birth years of case patients ranged from 1973 to 1992, with 94% (231) born in 1977 through 1992. Median age at the time of first chart mention of any alcohol-related diagnosis (i.e., fetal alcohol syndrome, fetal alcohol effects, or alcohol-related birth defects) was 8.4 months (range: birth to 16 years). The median age at first chart notation for fetal alcohol syndrome was comparable for Alaska Natives and non-Alaska Natives by birth cohort, with 1 exception: non-Alaska Native children born in 1977 through 1980 were significantly older at the time of syndrome recognition (median

^a Alaska Department of Health and Social Services.

TABLE 2-Fetal Alcohol Syndrome (FAS) Case Ascertainment by Source of Data: Alaska, 1977 to 1993

	Potential Cases Identified No.	Charts Abstracted No. (%) ^b	FAS Noted ^a No. (%) ^c	FAS Cases No. (%) ^c
Private sector				
Hospital, Fairbanks	16	16 (100)	12 (75)	4 (25)
Hospital, Anchorage	34	29 (85)	21 (72)	11 (38)
Pediatrician, Fairbanks	117	116 (99)	25 (22)	17 (15)
Pediatrician, Anchorage	44	38 (86)	10 (26)	7 (18)
Alaska Department of Health and Social Services				
Infant Learning Program Health Care Program for Children	31	24 (77)	17 (71)	14 (58)
with Special Needs	3	3 (100)	3 (100)	3 (100)
Clinic: cleft lip and palate	9	9 (100)	4 (44)	3 (33)
Clinic: genetics	50	50 (100)	23 (46)	18 (36)
Clinic: alcohol-exposed children	41	41 (100)	11 (27)	8 (20)
Rural nursing station	15	15 (100)	11 (73)	8 (53)
Medicaid claims	46	38 (83)	22 (58)	16 (42)
Birth certificates	20	17 (85)	4 (24)	2 (12)
Death certificates	3	1 (33)	1 (100)	1 (100)
IHS/Regional native health corporations				
IHS case file Regional native health corporations	218	190 (87)	124 (65)	81 (42)
(serving interior and southeast Alaska)	94	92 (98)	53 (58)	28 (30)
Native Medical Center, Anchorage	31	30 (97)	19 (63)	12 (40)
Total (unduplicated count)	630	568	248	145

Note. IHS = Indian Health Service.

age: 12.7 years) than Alaska Natives (median age: 2.8 years) (Kruskal–Wallis 1-way analysis of variance, P < .05; Table 3). Seventy-five percent of the case patients had an alcohol-related diagnosis mentioned in their chart by 3 years of age. Forty-three percent of the patients had been diagnosed with fetal alcohol syndrome or "probable fetal alcohol syndrome" by a dysmorphologist. Sixty-seven percent of those with known custody status (n = 127) were either adopted or in foster care.

The prevalence of fetal alcohol syndrome in Alaska was 0.8 per 1000 live births during 1977 through 1992. Among Alaska Natives, the prevalence of the condition ranged from a low of 1.4 per 1000 live births in 1977 to 1980 to a high of 4.1 per 1000 live births in 1985 to 1988 (Table 4). Among non—Alaska Natives, the prevalence ranged from a low of 0.1 between 1977 and 1984 to a high of 0.3 in 1989 through 1992.

The overall prevalence of a physician notation of fetal alcohol syndrome, with or without supporting documentation, was 1.3 per 1000 live births during 1977 through 1992. Among Alaska Natives, physician notation prevalence rates ranged from a low of 2.4 per 1000 live births in 1977 through 1980 to a high of 6.6 per 1000 live births in 1985 through 1988. For non-Alaska Natives, prevalence rates ranged from 0.2 per 1000 live births for the three 4-year

TABLE 3—Median Age and Year at First Medical Chart Notation of Fetal Alcohol Syndrome (FAS) by Birth Cohort, for FAS-Noted Cases (n = 231): Alaska, 1977 to 1992

Birth Years	No.	First Chart FAS Notation		
		Age, y, Median (Range)	Year, Mediar	
1989–1992				
Alaska Native	57	0.0 (0–2.8)	90.8	
Non-Alaska Native	16	0.5 (0–2.8)	91.1	
1985–1988				
Alaska Native	68	0.6 (0-7.0)	87.8	
Non-Alaska Native	7	0.4 (0-7.0)	88.1	
1981–1984				
Alaska Native	53	2.1 (0-9.0)	85.4	
Non-Alaska Native	7	2.9 (0–8.6)	87.3	
1977–1980				
Alaska Native	17	2.8 (0-16.1)*	84.0	
Non-Alaska Native	5	12.7 (7.5–13.9)	89.6	
Total	231	0.6 (0-16.1)	88.0	

^{*}P < .05 (Kruskal-Wallis one-way analysis of variance).

periods from 1977 through 1988 to 0.4 in 1989 through 1992.

Clinical Features and Characteristics of Biological Mothers

The most prevalent facial features noted were long or flat philtrum (70%), short palpebral fissures (66%), and thin

upper lip (52%) (Table 5). The most prevalent central nervous system impairments were developmental delay (76%), speech or language delay (41%), and microcephaly (37%). Eighty-one percent of the patients had some type of delay or learning disability. Sixty-four percent of patients had both a birthweight or birth height measurement and a postnatal weight or postnatal height

^a Physician chart notation of FAS suspected or diagnosed.

^b Percentage of potential cases identified.

^c Percentage of charts abstracted.

TABLE 4—Rates for FAS-Noted Individuals and FAS Case Patients per 1000 Live Births among Alaska Natives and Non-Alaska Natives: Alaska, 1977 to 1992

	Native		Non-Native		
Birth Years	FAS Noted, ^a Rate (No. Cases/Live Births)	FAS Cases, ^b Rate (No. Cases)	FAS Noted, ^a Rate (No. Cases/Live Births)	FAS Cases, ^b Rate (No. Cases)	
1989–1992	5.1 (57/11 065)	2.5 (28)	0.4 (16/36016)	0.3 (11)	
1985-1988	6.7 (68/10 150)	4.1 (42)	0.2 (7/38 010)	0.2 (6)	
1981-1984	5.9 (53/8971)	3.8 (34)	0.2 (7/37301)	0.1 (4)	
1977-1980	2.4 (17/7160)	1.4 (10)	0.2 (5/28 092)	0.1 (2)	
Total	5.2 (195/37 346)	3.0 (114)	0.3 (35/139419)	0.2 (23)	

Note. FAS = fetal alcohol syndrome.

measurement less than or equal to the 10th percentile. Fifty percent (72/145) were born at 37 weeks gestation or earlier. Other prevalent conditions noted included palmar crease anomalies (31%), digital or limb anomalies (clinodactyly, camptodactyly, syndactyly, polydactyly, club foot, limited extension of digits, shortened fingers, femoral or tibial torsion, valgus alignment of limbs; 30%), and strabismus (23%).

Sixteen case patients had no maternal identifiers available from medical chart abstraction. The remaining 129 patients were born to 111 women. Fourteen women gave birth to 32 case patients (22% of all patients). One woman alone gave birth to 4 case patients and to 3 other children who had a physician mention of fetal alcohol syndrome in their chart. In addition, 1 individual with a physician notation was the mother of another fetal alcohol syndrome case patient.

Birth certificates obtained for 102 case patients (70%) showed that 63% of mothers were not married at delivery and that 41% had not completed high school. (In contrast, for the general population, only 18% of Alaska mothers delivering between 1989 and 1993 had no or late prenatal care, and only 15% did not finish high school.¹⁹) The average number of living children born prior to the child with fetal alcohol syndrome was 2.4 (SD = 2.0). Sixty-nine percent of mothers either had no prenatal care (33%) or began prenatal care after the first trimester (36%). Medical charts and birth certificates documented an average maternal age at the time of delivery of 29 years (SD = 5.0, range = 15 to 45) and documented prenatal tobacco use for 39% of the case mothers. Medical charts mentioned cocaine use for 8% and marijuana use for 8% of the case mothers.

Usefulness of Data Sources in Fetal Alcohol Syndrome Surveillance

The Indian Health Service case file identified the largest proportion of cases

TABLE 5—Facial Features, Central Nervous System Impairments, Growth Characteristics, and Other Conditions Noted among Fetal Alcohol Syndrome Case Patients: Alaska, 1977 to 1992 (n = 145)

	Sample		
Feature/Characteristic	No.	%	
Facial features			
Long, flat philtrum	102	70	
Short palpebral fissures	96	66	
Thin upper lip	75	52	
Hypoplastic maxilla	56	39	
Flat nasal bridge	45	31	
Short nose relative to			
normal-length face	34	23	
2 or more features	115	79	
4 or more features	51	35	
Central nervous system impairment			
Developmental delay	110	76	
Speech/language delay	59	41	
Gross motor delay	32	22	
Fine motor delay	30	21	
Microcephaly	54	37	
Short attention span or attention-			
deficit disorder	40	28	
Learning disability or mental retardation	29	20	
Seizures	29	20	
Any delay or learning disability	118	81	
Growth characteristics			
Failure to thrive	32	22	
Birthweight (≤ 10th percentile)	107	74	
Birth length (≤ 10th percentile)	68	47	
Preterm delivery (≤ 37 weeks)	72	50	
Small for gestational age	62	43	
Postnatal weight (≤ 10th percentile)	106	73	
Postnatal height (≤ 10th percentile)	99	68	
Malformations and other conditions			
Palmar crease anomalies	45	31	
Digital or limb anomalies	43	30	
Strabismus	33	23	
Congenital heart disease	26	18	

(56%), followed by the regional native health corporations (19%) and the state's genetics clinic (12%). Other useful data sources included the Infant Learning Program, which identified 14 (29%) of the 49 case patients born between 1988 and 1992, and Medicaid claims, which identified 11% of all patients. In contrast, birth certificate data from 1989/90 identified only 2 (9%) of the 22 case patients born during those 2 years, and only 2 (12%) of the 17 individuals identified by the fetal alcohol syndrome check box on birth certificates met the case definition. Clinic data sources (state genetics and alcoholexposed children clinics and the Indian Health Service case file) identified 70% of all cases, and 65% of cases were uniquely identified by these sources.

Fifty-seven percent (13/23) of all non-Alaska Native cases identified by the state

^aPhysician chart notation of FAS suspected or diagnosed.

^bCase meets 5-criteria case definition for FAS.

were not identified by the private medical sector. In contrast, only 13% (16/121) of Alaska Native cases were not found in the Indian Health Service or regional native health corporation sources evaluated in this study.

Discussion

Our data indicate that 5 to 7 Alaska Native children per 1000 live births require follow-up evaluation because of suspected fetal alcohol syndrome. The greater fetal alcohol syndrome rates observed among Alaska Natives relative to non-Alaska Natives may be attributed, in part, to the extensive case finding activities of the Indian Health Service and to underascertainment of fetal alcohol syndrome in the latter group. Non-Alaska Natives were eligible to be identified in 13 of the 16 data sources examined. Despite these extensive case finding activities, the existing data sources yielded few non-Alaska Native cases. The rate of non-Alaska Native cases in the most recent birth cohort (1989 to 1992) was nearly twice that in the previous birth cohorts, and non-Alaska Native children in the younger birth cohorts had median ages at time of first chart mention of fetal alcohol syndrome that were comparable to those of Alaska Natives, suggesting that case ascertainment may be improving among the former. In addition, while some underascertainment of cases is likely for non-Alaska Natives, we do not believe that the observed difference in rates can be attributed entirely to differences in ascertainment between the 2 populations.

Differences in fetal alcohol syndrome rates by birth cohort may reflect poorer ascertainment among the oldest and youngest cohorts: children grow out of the facial dysmorphology of fetal alcohol syndrome during adolescence, 20 and young children have not had the same opportunity to be diagnosed. In a previous report exploring the use of capture-recapture analyses in fetal alcohol syndrome surveillance, half of the noted decrease in Alaska Native fetal alcohol syndrome rates (between 1982 to 1985 and 1986 to 1989) could be attributed to a lower case ascertainment rate among the youngest cohort.²¹ The remaining half of the noted decrease could reflect a true reduction in the fetal alcohol syndrome rate.

Racial and socioeconomic differences in fetal alcohol syndrome rates have been observed in other populations. Studies of White populations in the United States provide an incidence of fetal alcohol syndrome ranging from 0 to 1.3 per 1000 live births. ^{22–25} The birth defects monitoring program, which

relies on birth records, identified a fetal alcohol syndrome rate for the US population of 0.5 per 1000 live births.²⁶ Low socioeconomic status tends to be associated with higher fetal alcohol syndrome rates in most studies.²⁷ Fetal alcohol syndrome rates, according to the birth defects monitoring program, were 3.0 per 1000 births among US American Indians, 0.6 per 1000 births among Blacks, and 0.1 per 1000 births among Whites.²⁴ In South Dakota, a medical record review incorporating the same 5 criteria used in this study identified a fetal alcohol syndrome prevalence rate of 2.7 per 1000 Native American live births in 1981 through 1992.²⁸ Population-based fetal alcohol syndrome screening studies reported rates of 1.4 per 1000 births among Navajos, 2.0 per 1000 births among Pueblos, and 9.8 per 1000 births among the American Indians of the Southwest plains in 1980 through 1992.²⁹ Unfortunately, differences in the diagnosis and surveillance definitions of fetal alcohol syndrome among studies preclude direct comparisons of results. A standard surveillance definition is essential for comparing rates among different study populations.

Implications of Descriptive Characteristics for Fetal Alcohol Syndrome Prevention

The high prevalence of foster care, central nervous system impairments, and birth defects among the fetal alcohol syndrome case patients described here is consistent with the literature³⁰ and illustrates the high level of services needed by these individuals. The high percentage of mothers of case patients who had no or late prenatal care and had not completed high school emphasizes the need to identify creative ways to improve outreach to high-risk women. Inpatient and outpatient alcohol treatment centers may be one means of reaching women with educational and family planning services, and early education in schools regarding the effects of drinking during pregnancy may be indicated. Alcohol and other substance abuse may contribute to or be a covariate of dropping out of school, and continuation of substance abuse may be more likely among school dropouts. 31 Reducing the prevalence of school dropout and substance abuse among young women may play an indirect role in reducing the prevalence of high-risk women. Also, the high percentage of patients in adoptive or foster care homes suggests that the child protective service system may present an opportunity to identify and refer alcohol-abusing women of childbearing age to needed services. In a previous study, children with fetal alcohol syndrome lived with, on average, 5 different caretakers in their lifetimes, and only 9% lived with both of their biological parents.²⁰

Usefulness of Data Sources

The finding that 65% of all case patients were uniquely identified by active screening and referral programs for specialty diagnostic clinics illustrates the magnitude of underreporting by all of the passive reporting data systems. Birth certificates and hospital discharge summaries of live births did not yield sufficient numbers of cases to be considered important data sources. Given the difficulty in diagnosing cases at birth³² and in identifying fetal alcohol syndrome through birth records,³³ the federal requirement that maternal child health block grant recipients monitor and report annually the proportion of live births involving fetal alcohol syndrome (House Resolution 2651, Improvement Amendment) should be reevaluated. Medicaid data may be a useful source for fetal alcohol syndrome surveillance. Medicaid tapes in other states may detect a greater percentage of all known cases than they did in this report, because Medicaid claims for Indian Health Service or the regional native health corporations in Alaska are billed directly to the federal government and are not included in the state data tapes. In addition, infant learning programs may be a promising source of surveillance data, especially with the new legislation entitling children with fetal alcohol syndrome to early childhood intervention services.

Limitations

Because of this report's reliance on medical chart notations, which are most likely underrepresentative of fetal alcohol syndrome, the rates observed may have been lower than the true rates in the population. The extent of underascertainment due to missing or incomplete medical charts is difficult to determine. Also, some degree of underascertainment may have occurred because no attempt was made to identify records from all pediatric practices and hospitals. However, the low number of unique cases identified from hospital discharge data tapes and pediatric practices suggests that use of additional hospitals and pediatric practices would not have substantially changed the overall observed rates. Another limitation to these data is the likelihood that a portion of the individuals meeting the five case definition criteria may not actually have had fetal alcohol syndrome.

In summary, fetal alcohol syndrome surveillance is problematic; a broad and vague continuum of effects have been associated with fetal alcohol exposure, the diagnosis is subjective, there are age differences in the expression of the phenotype, and the ICD-9 code (760.71) used to denote fetal alcohol syndrome is nonspecific. In addition, no single data source appears to be adequate in enumerating the population, and the lack of standard diagnostic and surveillance case definitions for fetal alcohol syndrome presents problems in making any meaningful comparisons among different study populations.

Recommendations

While we recommend the use of multiple data sources, complete enumeration of fetal alcohol syndrome cases using all data sources is costly and time consuming. Therefore, we recommend reliance on data sources with the greatest potential to identify cases, recognizing that rates based on these sources will provide a minimum estimate of the prevalence of fetal alcohol syndrome. In addition, combining surveillance resources with existing programs designed to serve affected children may provide a cost-effective approach to surveillance. Finally, population-based screening studies, which may provide the most reliable estimate of fetal alcohol syndrome prevalence, may be too expensive and time consuming for ongoing surveillance in the general population.

Despite the many inherent difficulties in enumerating fetal alcohol syndrome, surveillance efforts in Alaska have yielded important information on the administrative prevalence rates of fetal alcohol syndrome in the state and on the characteristics of the case children and their mothers. Important data sources for determining the prevalence of fetal alcohol syndrome in a population have also been identified. These data provide the background information needed to design an ongoing surveillance system to track trends in fetal alcohol syndrome and provide some of the descriptive information needed on the mothers of fetal alcohol syndrome children to guide prevention efforts. \square

Acknowledgments

We would like to acknowledge the contributions of Kaye Saxon in preparing the manuscript, Drs Bruce Chandler and Carl Li for their assistance in abstracting medical charts, and Mr Al Zangri for providing vital statistics data. Also, we thank Donna Fenske; Drs Marvin Bergeson, Donald Pickering, and Clin-

ton Lillibridge; the Tanana Chiefs Conference; and the Southeast Alaska Regional Health Corporations for making medical charts available for review. Finally, we thank Tony Story and Alma Mullen for clerical support in pulling and tracing the whereabouts of hundreds of medical charts and the many members and friends of the Alaska Fetal Alcohol Syndrome Prevention Project Steering Committee for their valuable insights during the development of this work, including Marvin Bailey, Vicki Hild, Dr Sterling Clarren, Elaine McKenzie, and Karen Pearson.

References

- 1. Sokol RJ, Clarren SK. Guidelines for use of terminology describing the impact of prenatal alcohol on the offspring. Alcohol Clin Exp Res. 1989;13:597-598.
- 2. Abel EL, Sokol RJ. Incidence of fetal alcohol syndrome and economic impact of FASrelated anomalies. Drug Alcohol Depend. 1987;19:51-70.
- 3. Dorris, M. The Broken Cord. New York, NY: Harper & Row Publishers Inc; 1989.
- 4. Abel EL, Sokol RJ. A revised conservative estimate of the incidence of fetal alcohol syndrome and its economic impact. Alcohol Clin Exp Res. 1991;15:514-524.
- 5. Jones KL, Smith DW, Ulleland CN, et al. Pattern of malformation in offspring of chronic alcoholic mothers. Lancet. 1973;1:1267-1271.
- 6. Hanson JW, Jones LK, Smithe DL. Fetal alcohol syndrome: experience with 41 patients. JAMA. 1976;235:1458-1460.
- 7. Clarren SK, Smith DW. The fetal alcohol syndrome. N Engl J Med. 1978;298:1063-1067.
- 8. Ammann AJ, Wara DW, Cowan MJ, et al. The DiGeorge syndrome and fetal alcohol syndrome. Am J Dis Child. 1982;136:906-908.
- National Center for Health Statistics. Healthy People 2000 Review, 1993. Hyattsville, Md: Public Health Service; 1994.
- 10. Adams WL, Yuan Z, Barboriakk JJ, Rimm AA. Alcohol-related hospitalizations of elderly people. JAMA. 1993;270:1222-1225.
- 11. Apparent per Capita Alcohol Consumption: National, State, and Regional Trends, 1987-1989. Washington, DC: US Dept of Health and Human Services; 1991. Surveillance report 20.
- 12. Centers for Disease Control and Prevention. Frequent alcohol consumption among women of childbearing age-Behavioral Risk Factor Surveillance System, 1991. MMWR Morb Mortal Wkly Rep. 1994;43:328-335.
- 13. Centers for Disease Control and Prevention. Prevalence and characteristics of alcohol consumption and fetal alcohol syndrome awareness in Alaska. MMWR Morb Mortal Wkly Rep. 1994;43:3-6.
- 14. The littlest victims suffer wrath of FAS [editorial]. Anchorage Daily News. January 13, 1988:B-9.
- 15. International Classification of Diseases, 9th Revision: Clinical Modification. Washington,

- DC: US Dept of Health and Human Services; 1980. DHHS publication PHS 80-1260.
- 16. Hamil PV, Drizd TA, Johnson CL, et al. Physical growth: National Center for Health Statistics percentiles. Am J Clin Nutr. 1979;32:607-629.
- 17. Dibley MJ, Goldsby JB, Staehling NW, Trowbridge FL. Development of normalized curves for the international growth reference: historical and technical considerations. Am J Clin Nutr. 1987;46:736-748.
- 18. Clarren SK, Astley SJ. A Screening Guide for Fetal Alcohol Syndrome. Washington, DC: US Dept of Health and Human Services; 1993.
- 19. Dept of Health and Social Services. Juneau, Alaska: Bureau of Vital Statistics, Dept of Health and Social Services, State of Alaska, August 1994. Special report.
- 20. Streissguth AP, Aase JM, Clarren SK, et al. Fetal alcohol syndrome in adolescents and adults. JAMA. 1991;265:1961-1967.
- 21. Egeland GM, Perham-Hester KA, Hook EB. Use of capture-recapture analyses in fetal alcohol syndrome surveillance in Alaska. Am J Epidemiol. 1995;141:335-341.
- 22. Kuzma JW. Sokol RJ. Maternal drinking behavior and decreased intrauterine growth. Alcohol Clin Exp Res. 1982;6:396-402
- 23. Hanson JW, Streissguth AP, Smith DW. The effects of moderate alcohol consumption during pregnancy on fetal growth and morphogenesis. J Pediatr. 1978;92:457-460.
- 24. Chavez GF, Cordero JF, Becerra JE. Leading major congenital malformations among minority groups in the United States. MMWR Morb Mortal Wkly Rep. 1988;37:17-24.
- 25. Croen L, Schulman J, Roeper P. Birth Defects in California. Sacramento, Calif: California Birth Defects Monitoring Program; 1990.
- 26. Cordero JF, Floyd RL, Martin ML, et al. Tracking the prevalence of fetal alcohol syndrome. Alcohol Health Res World. 1994;18:82-85.
- 27. Bingol N, Schuster C, Fuchs M, et al. The influence of socioeconomic factors on the occurrence of fetal alcohol syndrome. Adv Alcohol Subst Abuse. 1987;6:105-118.
- 28. Centers for Disease Control and Prevention. Use of International Classification of Disease coding to identify fetal alcohol syndrome-Indian Health Service facilities, 1981-1992. MMWR Morb Mortal Wkly Rep. 1995;44: 253-261.
- 29. May PA, Hymbaugh KJ, Aase JM, Samet JM. Epidemiology of fetal alcohol syndrome among American Indians of the Southwest. Soc Biol. 1983;30:374-387.
- 30. Abel EL. Fetal Alcohol Syndrome. Oradell, NJ: Medical Economics Co Inc; 1990.
- 31. Dryfoos JG. Adolescents at Risk: Prevalence and Prevention. New York, NY: Oxford University Press Inc; 1990.
- 32. Little BB, Snell LM, Rosenfeld CR, et al. Failure to recognize fetal alcohol syndrome in newborn infants. Am J Dis Child. 1990;144: 1142-1146.
- 33. Centers for Disease Control and Prevention. Fetal alcohol syndrome-United States, 1979-1992. MMWR Morb Mortal Wkly Rep. 1993;42:339-341.